TASK FORCE ON THE YOUNG DISABLED

A REPORT TO THE
MINISTER OF HEALTH
PROVINCE OF MANITOBA

JANUARY, 1984

Manitoba

Health

Manitoba Health
Services Commission

P.O. Box 925
599 Empress Street
Winnipeg, Manitoba, CANADA
R3C 2T6

January 23, 1984

Honourable L. L. Desjardins
Minister of Health
Government of Manitoba
7th Floor - 175 Hargrave Street
Winnipeg, Manitoba
R3C 3R8

Dear Mr. Desjardins:

In accordance with the terms of reference set out for our Task Force, we have completed and are pleased to submit our report on "The Young Disabled in Personal Care Homes."

Yours truly,

Kay Thomson

Mrs. K. Thomson
Chairman
Task Force on the Young Disabled

KT/cjl

Encl.

Manitoba Youth Moving Ahead
International Youth Year 1985

MEMBERS OF THE TASK FORCE

R. Asselin

C. Sarchuk

T. Bains

E. Thompson

B. Havens

M. Watts

J. Zamprelli

TABLE OF CONTENTS

		PAGE
I.	INTRODUCTION	1
II.	TERMS OF REFERENCE	3
III.	REVIEW OF VISITS, INTERVIEWS AND DEMOGRAPHIC DATA	4
IV.	POLICY DEVELOPMENT	10
V.	LIVING ARRANGEMENT OPTIONS	12
VI.	DISABLED IN THE WORKPLACE	19
VII.	HOME CARE	20
APPENDICES:		25
	APPENDIX A - MEMBERS OF THE TASK FORCE	26
	APPENDIX B - FACILITIES VISITED BY TASK FORCE MEMBERS	27
	APPENDIX C - GROUPS RESPONDING TO CALL FOR SUBMISSIONS	28
	APPENDIX D - ALTERNATE HOUSING MODELS - A CROSS CANADA PERSPECTIVE	29
	APPENDIX E - DEMOGRAPHIC DATA AND PROFILE	36

I. INTRODUCTION

In 1982 the Manitoba Council on Aging issued a report on the Young Disabled in Personal Care Homes. In this report, they took the position that the Young Disabled should have separate facilities from the elderly in personal care homes. In addition, the Council was of the opinion that "the young disabled person should be given a variety of options in living arrangements." The Council put forth the following recommmendation:

"That a provincially sponsored Task Force be appointed to examine what is available across the nation and to recommend action by the Province and others to create appropriate options in living arrangements for the young disabled."

In response, the Minister of Health called for the formation of an Interdepartmental Task Force on the Young Disabled.

In January 1983, an 8 member Task Force comprised of representatives from several governmental departments was established (see Appendix A). In an interim report to the Minister on April 26, 1983, the Task Force asked for and received approval to expand its initial mandate from specifically addressing the needs of the Young Disabled in Personal Care Homes to include those Young Disabled receiving Home Care in a variety of community settings.

In the initial stages of its deliberations, the Task Force identified the Young Disabled as those between the ages of 18 and 64. Subsequently, the age group between 60-64 was dropped from the mandate, as diagnostic categories indicated that most often these individuals were appropriately placed in personal care homes. Their social needs were also considered to be reasonably similar to those residents of personal care homes 65 years of age and over; hence they were considered to be less appropriate candidates for alternate strategies than those under the age of 60.

Age parameters were developed only for purposes of retrieving and compiling statistical information. It is acknowledged that needs identified here are not exclusive to those individuals between the ages of 18 and 59 and that the content of this report has implications for individuals of all ages. Therefore, references throughout the body of this report will be made to "adult disabled" rather than "young disabled" persons.

Those disabled persons under the age of 18 were not included in the work of the Task Force, The Task Force however, has acknowledged that this population will experience changing needs as they reach young adulthood and that the recommendations of the Task Force will have implications for their future.

A disabled person, in the context of this report, is one whose handicaps in daily living are chronic (stable or unstable). These handicaps may result from a condition of birth or from accident or disease at any age, and are not generally associated with the normal aging process.

The Task Force's recommendations were developed through compilation and examination of demographic data and review of information requested and received from other provinces and from visits and interviews with both the disabled residents and the staff and administration of personal care homes, hospitals and community programs (See Appendix B). In addition, submissions were requested and a number of interested groups responded (See Appendix C).

II. TERMS OF REFERENCE

The terms of reference as given to the Task Force and subsequently expanded were:

1. To identify the nature of the needs and concerns of the young disabled in personal care homes.

2. To examine options in living accommodations and services available to young disabled persons across Canada and to make recommendations regarding the options which should be provided for young disabled persons in Manitoba.

3. To develop planning strategies with regard to young disabled who are receiving Home Care services in a variety of settings.

III. REVIEW OF VISITS, INTERVIEWS AND DEMOGRAPHIC DATA

To fully explore the needs and concerns of those adult disabled persons presently resident in personal care homes, and those awaiting placement, members of the Task Force visited twelve facilities to interview administration, staff and residents (see Appendix B). Five personal care homes in Winnipeg, two in Brandon and two in smaller rural centers were visited. In addition, two Winnipeg hospitals and one transitional facility were included in the survey.

These facilities varied in overall size and particularly in the ratio of adult disabled to elderly persons. Generally, in those facilities with few adult disabled residents, concerns seemed to center primarily around physical needs, loneliness and the lack of peer and family contact. In facilities with a larger ratio of younger disabled adults, residents identified developmental and self-actualization concerns (e.g. job and educational opportunities) more readily. Despite these variations, certain trends relating to physical and psychosocial needs were evident throughout. The following two sections present a synopsis of the interviews conducted with disabled residents and with staff and administration in the facilities visited.

A) CONCERNS RAISED BY ADULT DISABLED RESIDENTS OF PERSONAL CARE HOMES AND OTHER FACILITIES:

There is a great variation in the response of adult disabled residents in personal care homes from resignation to total dissatisfaction and requests for transfer to other facilities.

The major concern centered around the lack of opportunity for social interaction with peers. Adult disabled residents feel that they have little in common with the elderly residents. Programs designed to meet the needs and interests of the elderly, and a lack of evening programming are cited as negative aspects of some personal care home programs. In addition, insufficient educational opportunities (especially in rural areas) is an area of concern.

Some younger disabled adults express a need for opportunities to be productively employed. Job related responsibilities in the personal care home filled this expressed need for usefulness and self worth for some residents.

Lack of privacy is an issue often raised. The fact that "everyone knows your business" and being disturbed by wandering and disoriented elderly persons are given as examples.

Transportation costs, particularly for recreational purposes, and difficulty in accessing special transportation at certain times of the day are also cited as limitations to a more independent lifestyle.

Although the adult disabled residents in personal care homes are able to identify a number of concerns regarding lifestyle and unmet needs, many could not conceive of other alternatives primarily because of their concern about the high levels of care and assistance they require. Many feel that they are appropriately placed, and are not able to express concerns about living in a personal care home. On the other hand, one resident has asked for a transfer to a another facility where there is a higher ratio of young disabled residents to elderly residents, despite having to leave family and friends. The need for contact with individuals of the same age range was the deciding factor.

When presented with possible alternative models for accommodation, concern is expressed about the need for staff and support systems around the clock, particularly in times of emergency. There is considerable doubt as to whether this type of support could be provided in models other than personal care homes. The alternatives which represented the least change from a personal care home are often felt to be the most attractive (e.g. a wing of a personal care home designated for young disabled residents). "Living with other younger people, perhaps in a smaller facility but with the same levels of support as a personal care home," was offered as an alternative.

B) ISSUES RAISED BY ADMINISTRATION AND STAFF OF PERSONAL CARE HOMES AND OTHER FACILITIES:

When discussing those adult disabled persons resident in personal care homes, the major concern centered around the lack of appropriate socialization and opportunities for meaningful interpersonal contacts. Special needs are seen to be primarily related to social needs. Loneliness is more apparent among disabled adults than among elderly residents, and the need for peer relationships is identified as the main causative factor. It is felt that most adult disabled interact very little with the elderly population. Their social needs are mainly met through contact with staff, volunteers, friends, family and other younger residents of the facility. Adult disabled residents tend to group together spontaneously in most facilities. In some rural areas, this is seen as less of a concern; perhaps attitudes are different, as there would appear to be more interaction between the various age groups.

Twenty to twenty-five percent would seem to be the minimum proportion of young disabled adults in a personal care home required to provide opportunities for appropriate and satisfying social interaction. In absolute terms, the number should not be less than between eight and twelve individuals. Outreach into community programs could help to fill this need; however, often demands on community services are so great that personal care home residents are not included. In addition, special transportation requirements for recreational purposes have a low priority in the transportation sector, and the costs of special transportation can be prohibitive to the residents.

Staff and administration of care facilities identified a number of concerns held by disabled adults with regard to personal care homes. The attitudes of the adult disabled persons who are being considered for placement in personal care homes are perceived by staff to be primarily negative. The first reaction is to the stigma attached to the term "nursing home." The inevitable association with people over the age of eighty, and the finality associated with being a resident in a personal care home, are also expressed. Also, the separation from spouse and/or family is a concern. There is also a feeling that the care provided in personal care homes implies a loss of independence, even though individuals may already be receiving an equivalent amount of assistance or care at home or in hospital.

The disabled adults in personal care homes are felt to require more than the elderly in terms of rehabilitation, therapy, recreational opportunities, activities, job opportunities and community contacts and involvement. Job opportunities and occupational programs were considered to be important, but difficult to provide. For many, specialized recreational and educational programs and opportunities for more intense physical activity are required. Special training for staff members working with the younger residents is also identified as a need.

Personal care homes by and large, are not equipped to provide the privacy that younger residents require. The provision of "Habitation Suites" where residents could visit with spouses and/or families was discussed. It was felt that other residents and staff often have difficulty in dealing with the issue of intimacy and the need for special training of staff was related to this issue.

Residents with behavioural problems tax the personal care homes' resources beyond what they feel they are able to provide. Younger residents with behavioural problems are felt to be more difficult to manage than the behaviourally disturbed elderly. Many facilities feel that some of these individuals are inappropriately placed in personal care homes.

Resident councils are seen to be an important mechanism for retaining feelings of independence and autonomy. Adult disabled residents in one facility have their own council which relates in turn to both administration and the separate council of the elderly residents.

Financial supports to adult disabled residents are generally felt to be inadequate. They should have the same financial supports as the elderly. In some instances there is a financial disincentive for a resident to leave the personal care home and move to a community setting because of the higher costs of community living (e.g. rent/board and room, medication and other related costs).

The present population of adult disabled residents of personal care homes who were born before advances in rehabilitation have, by and large, accepted living in a personal care home; however, there is a concern that younger disabled persons who have experienced intensive rehabilitation, integrated schooling and social opportunities will not readily accept personal care home placement.

When discussing alternatives to personal care home placement the following broad groupings of adult disabled were identified by staff and administration:

1. Those individuals who are able to live independently, with or without supports.

   Generally, these individuals have a known functional level which is not expected to change significantly. They are capable of a fairly high degree of self determination, and are able to direct resources and exercise independent judgement in the management of daily living. These individuals are able to continue to live at home, or are able to benefit most from living in existing facilities (e.g. Ten Ten Sinclair, Fokus).

2. Those individuals who are not able to live independently.

   This group is made up of two sub-groups for whom there is no suitable alternative placement at present.

i. Those with progressively deteriorating conditions who require a fairly high level of care, but need the privacy and opportunity for independence that personal care homes cannot provide. This group will require continuous therapeutic intervention and a more communal approach to living accommodation.

ii. Those who have organic brain disorders and who may or may not have emotional and behavioural problems. These individuals are generally unable to direct their own lifestyle or manage resources and therefore require supervision and a supportive environment. One proposed alternative is a small facility, similar to a personal care home which could combine both a "transitional" type of accommodation together with long term placement. It would be staffed and equipped to deal with the special needs of this group. The main emphasis would be on the provision of a high degree of supervision, decision making and attention to personal safety with intensive social and recreational planning.

A recurring concern with care-givers is the need for options in accommodation. Just as other members of society have options, so should disabled individuals have options within a full range of facilities. It was felt that adult disabled residents, after placement in personal care homes, often became very apprehensive of less dependent settings, therefore the importance of providing a range of residential alternatives early in the placement process becomes significant.

C) SUMMARY OF DEMOGRAPHIC DATA

To assist the Task Force in its deliberations and consistent with the Terms of Reference, data was collected from relevant government programs which identified the characteristics of those adult disabled persons resident in personal care homes, those waiting for personal care home placement and those in receipt of services in the community. Those characteristics are summarized in this section and more complete detail is contained in Appendix E.

In total, there were 249 individuals under the age of sixty in personal care homes at the time the data was compiled (March 1983). Most were at the upper end of the

age range; when divided in three age groups, the young (24-35 years), the middle (36-47 years), and the eldest (48-59 years), nearly three-quarters (71.4%) were in the eldest category. Only six percent were in the youngest grouping, with the remaining 23% in the middle group. When the one case below the age of 24 is excluded, there are exactly the same number of men and women (124).

In percentage terms almost two-thirds (63.7%) of this group of disabled persons in personal care homes are in the Winnipeg region. Since only 55% of Manitoba's population aged 18 to 59 years lives in the region, Winnipeg is overrepresented in terms of this group. Based on population, Westman and Parklands region are also overrepresented. These three regions account for 85% of this group. The others are underrepresented, having less than their share based on population.

While this group of disabled individuals is older than the population at large, they are much younger than most other personal care home residents, whose average age is 83 (the average age of these disabled persons is about 50 years). Though they are almost equally likely to be men as women, men are more likely to have the diagnosis of a central nervous system dysfunction plus a systemic disease while women are more likely to have the diagnosis of multiple sclerosis. These adults are most likely to live in the Winnipeg region, followed by Westman and Parklands.

There are, as noted earlier, 249 adults with disabilities between the ages of 18 and 59 years residing in personal care homes in Manitoba. There is a similar group of 31 adults that were, in March 1983, waiting for a place in a personal care home. On the whole, these individuals were younger than the same group already in personal care homes. The average age of those awaiting placement was about 47 years as compared to 50 years for the resident group. Unlike the resident group of younger disabled persons, in which men and women were very nearly equal in number, the group awaiting placement were more likely to be female (61.3%).

Among both personal care home residents and those waiting placement, there are 60 individuals with the specific diagnosis of mental retardation or mental illness. These individuals are more likely to be male, unlike both the larger waiting list and the overall resident group.

IV. POLICY DEVELOPMENT

DISCUSSION:

At the present time there is no agency or department of government that has the mandate to coordinate services available to the adult disabled. Between the points in chronological age at which legislation governing child welfare ends and senior citizen status is reached, and where individuals are not covered by the mandate of the Mental Retardation or Mental Health programs, there is no service or program stream that addresses the needs of the adult physically disabled. If the responsibility for planning and coordination is not vested in an identified body and unless action is taken, individual pressure groups will continue to request governmental intervention, resulting in continued fragmentation of services.

In addition to those issues dealt with further in this report, other issues which need to be addressed by such a coordinating body include: development of educational resources, the need for appropriate day centres and legal and financial planning, etc.

RECOMMENDATIONS:

1. THAT AN IDENTIFIABLE BRANCH OF AN APPROPRIATE DEPARTMENT OF GOVERNMENT, AS DETERMINED BY CABINET, BE ESTABLISHED TO ACT IN COLLABORATION WITH OTHER GOVERNMENTAL AND PRIVATE AGENCIES TO ENSURE THE COORDINATED PLANNING AND DEVELOPMENT OF PROGRAMS AND SERVICES FOR ADULT DISABLED PERSONS.

2. THAT THIS COORDINATING BODY ALSO BE RESPONSIBLE FOR THE ESTABLISHMENT OF PROVINCIAL PRIORITIES FOR PROGRAMS, SUPPORT SERVICES AND HOUSING ALTERNATIVES FOR ADULT DISABLED PERSONS.

3. THAT THE NEED FOR CONSUMER INPUT TO THIS COORDINATING BODY BE ACKNOWLEDGED BY THE APPOINTMENT OF AN ADVISORY COUNCIL WHICH WOULD INCLUDE REPRESENTATION FROM MEMBERS OF THE DISABLED COMMUNITY.

4. THAT ISSUES RELATING TO THE NEEDS OF ADULT DISABLED PERSONS IN THE WORKPLACE BE FURTHER REVIEWED, AND IMPLEMENTATION STRATEGIES BE DEVELOPED BY THIS COORDINATING BODY (SEE SECTION VI, PAGE 19).

DISCUSSION:

At present the Social Services Administration Act and Regulations relative to Residential Standards and Licensing specifically exclude those physically disabled persons under the age of 65 who are neither mentally retarded nor post-mentally ill. While the Residential Standards and Licensing Branch makes every effort to implement the standards for all those living in residential care facilities, the regulations under the Act preclude both this branch and any other branch from addressing concerns relative to assessment, evaluation, income security and placement alternatives for the adult disabled individual.

RECOMMENDATION:

5. THAT LEGISLATION GOVERNING THE MANDATE OF RESIDENTIAL STANDARDS AND LICENSING SHOULD BE AMENDED TO INCLUDE THOSE DISABLED PERSONS UNDER THE AGE OF 65 WHO ARE NEITHER MENTALLY RETARDED NOR POST-MENTALLY ILL.

DISCUSSION:

Those disabled adults living in personal care homes and residential care facilities have particular needs in the areas of socialization, employment, education, etc. and they require special financial consideration to enable them to meet these needs and to maintain contact with the community at large. One solution is to ensure that these individuals receive adequate disposable income to meet these needs. Those adult disabled persons living in the community have similar needs, and where earned income or current income security programs do not provide sufficient resources to meet these needs, allocating supplementary resources would provide a solution.

RECOMMENDATION:

6. THAT THE DISPOSABLE INCOME OF ADULT DISABLED PERSONS BE INCREASED TO BE AT LEAST EQUIVALENT TO THAT RECEIVED BY THOSE AGED 65 AND OVER, SO THAT THEIR SPECIAL NEEDS CAN BE MET AND SO THEY CAN MAINTAIN THEIR INVOLVEMENT WITHIN THE COMMUNITY AT LARGE.

V. LIVING ARRANGEMENT OPTIONS

Housing and living arrangements for disabled persons across Canada have been conceptualized, designed, developed and managed with the intent of providing shelter and support which accommodates the individual's capacities and desire for self-management. There are a variety of options in housing form, design and tenure, in the type and mandate of support personnel, and in opportunities for participation of disabled persons in the design, operation and management of the living arrangement. These options range from "least normalized" to "most normalized" in relation to the opportunities they present for integration into the mainstream of society and for maintaining optimum independence and self control.

Living arrangements for disabled persons must address or respond to either or both of the following variables:

a) The amount of supportive services he/she needs within the living environment to meet physical needs which are the consequence of a physical disability.

b) The degree of independence or dependence the individual has in coping with mental, social and emotional needs resulting from the disability or as a consequence of an individual taking steps toward community integrated, independent living.

For purposes of discussion, four types of living arrangements available to younger disabled individuals across Canada, will be described. More detailed profiles of existing facilities and accommodations are contained in Appendix D.

A. QUASI-INSTITUTIONAL CARE FACILITIES

Some examples of this type of living arrangement provide for a greater degree of independence than personal care homes in Manitoba. Of the models identified in Appendix D, this one provides the least opportunity for decision making and personal independence. Although the administration of these facilities are committed to fostering independent development of residents, this type of living arrangement seems to exhibit a quasi-institutional atmosphere. Such models may be appropriate options for those individuals presently in personal care homes or awaiting placement, who require a "care environment" but prefer to live with peers (See Appendix D, Part A).

B. TRANSITIONAL HOUSING

The objective of this type of living arrangement is to assist residents in developing self management skills which will prepare them for more independent community living. Manitoba's commitment to Ten Ten Sinclair exhibits proven expertise in providing a transitional living experience. It should be recognized however that "transitional living" need not only take place in a facility specifically built for that purpose. Experience demonstrates that the potential for transition is always present no matter where an individual is currently situated (See Appendix D, Part B).

C. GROUP LIVING (GROUP HOMES/COMMUNITY RESIDENCE)

This living arrangement allows the disabled adult to live among peers, sharing and receiving help in various aspects of activities of daily living while attaining physical and emotional security. This option can take place in a single family home, one apartment unit or in a cluster of apartments. This option has been used in Manitoba only for those individuals whose disability is mainly of a mental/developmental nature, and has not been utilized for those with primarily physical disabilities.

The group living option merits investigation for further adaptation in Manitoba especially for physically disabled adults who are seeking environments which provide a structural component of emotional support and ongoing assistance in the development of life skills.

The group living option may offer an alternative for individuals who are not able to deal with the insecurity that community integrated, independent living might entail (See Appendix D, Part C).

D. INDEPENDENT LIVING WITH SUPPORT

This type of living arrangement provides the most normalized living environment. The characteristics comprise integrated, apartment style living as part of a larger housing complex (public or private sector) as well as the provision of attendant care personnel. The provision of service is designed around a group of individuals whose physical care needs are at a high level but who are emotionally or socially independent and capable of self-direction regarding activities and decisions of daily living.

Fokus Manitoba is a proven example of the successes and benefits which result from independent, apartment style living with support.

The other examples of this approach across Canada should be examined in more detail to determine what aspects of organization, staff functions, entry and exit systems could possibly serve as models to modify and enhance Fokus Manitoba (See Appendix D, Part D). The success of Fokus Manitoba suggests that this model be continued and further expanded throughout the province.

A variation of this concept includes independent living on a more individualized basis, for example, where persons own or rent self-contained housing units and where support from family, informal or formal care providers enables them to remain at this level of normalized, integrated living.

DISCUSSION:

Independence is relative to the degree of one's disability and the degree to which the individual is committed to work towards such a goal. Living options should accommodate the spectrum of potential levels of independence and assist the individual to reach and maintain his or her maximum capability. Examples of the Government of Manitoba's commitment to providing such opportunities include: Ten Ten Sinclair, Kiwanis Centre of the Deaf and Fokus Manitoba.

RECOMMENDATION:

1. THAT THE GOVERNMENT OF MANITOBA, THROUGH AGENCIES MANDATED TO WORK WITH AND SERVE THE NEEDS OF DISABLED PERSONS, CONTINUE A COMMITMENT TO DEVELOPING HOUSING/LIVING ARRANGEMENTS THROUGHOUT THE PROVINCE WITH SUPPORT SERVICES WHICH OFFER THE MOST NORMALIZED, INDEPENDENT LIVING ENVIRONMENTS WHERE THE INDIVIDUAL CAN ACHIEVE HIS/HER OWN MAXIMUM LEVEL OF SELF-DIRECTION AND CONTROL OF DAILY LIVING.

DISCUSSION:

As a result of its dialogue with some adult disabled residents of personal care homes, and potential residents of care institutions, the Task Force feels that there is a need to develop living arrangements previously identified as quasi-institutional. This is viewed as a priority area for action, as there are no facilities of this type in Manitoba.

RECOMMENDATION:

2. GIVEN THAT SOME DISABLED PERSONS IN PERSONAL CARE HOMES, FOR A VARIETY OF REASONS, CONSIDER THESE FACILITIES TO BE THEIR "HOMES" AND FEEL MOST COMFORTABLE AND SECURE IN SUCH CARE ENVIRONMENTS, GOVERNMENT SHOULD SUPPORT:

   a) DEVELOPMENT OF PERSONAL CARE HOME PROGRAMS WHICH WOULD BETTER ACCOMMODATE AND BE MORE RESPONSIVE TO THE LIFE-STYLE OF THE YOUNGER RESIDENT.

   b) DEVELOPMENT OF ALTERNATIVES SEPARATE FROM EXISTING FACILITIES. THIS SEPARATION COULD TAKE THE FORM OF A WING OR MODULE RELATED TO AN EXISTING FACILITY OR A SMALL SCALE, FREE STANDING HOME WHERE THE PHYSICAL DESIGN AND STAFFING ARE PLANNED PRIMARILY FOR THE YOUNGER DISABLED PERSON.

3. a) THAT FUNDING BE ALLOCATED FOR ESTABLISHING AND IMPLEMENTING GROUP LIVING AND QUASI- INSTITUTIONAL FACILITIES.

   b) THAT PRIORITY BE GIVEN TO ESTABLISHING A QUASI-INSTITUTIONAL FACILITY IN WINNIPEG. THE SIZE OF THIS FACILITY SHOULD BE DETERMINED IN CONSULTATION WITH THE ADVISORY COUNCIL RECOMMENDED IN SECTION IV, RECOMMENDATION 3, PAGE 10.

4. THAT CONSIDERATION BE GIVEN TO PROVIDING FOR "HABITATION SUITE(S)", WHERE RESIDENTS MAY VISIT WITH SPOUSES AND/OR FAMILIES, WITHIN FACILITIES DEVELOPED FOR YOUNGER DISABLED PERSONS.

DISCUSSION:

Development of group living/shared accommodations is viewed as another priority as this option is not currently available in Manitoba for this type of need group. Group living can take place in either newly-constructed, purpose built residences, in renovated existing structures or through clustering of apartment units.

Development of this option could be based on the Cheshire Home models (See Appendix D, Part C). Size would be determined in part by the age and sex mix of the residents, by their physical, emotional and life skills developmental needs and, by the nature of the required support staff.

RECOMMENDATION:

5. THAT THE GOVERNMENT OF MANITOBA SUPPORT THE DEVELOPMENT OF "GROUP LIVING ARRANGEMENTS" (SHARED ACCOMMODATIONS) TO MEET THE NEEDS OF THOSE PHYSICALLY DISABLED PERSONS WHO DESIRE A COMMUNAL LIVING STYLE AND WHO DESIRE OR REQUIRE SUPERVISION AND ASSISTANCE IN DAILY LIVING MANAGEMENT (E.G. HEALTH, MEALS, HOUSEHOLD, FINANCIAL, VOCATIONAL/ RECREATIONAL MANAGEMENT).

RECOMMENDATIONS:

6. a) THAT TEN TEN SINCLAIR BE VIEWED AS A VALUABLE PROVINCIAL RESOURCE FOR THOSE DISABLED PERSONS WHO REQUIRE THE PARTICULAR SERVICES OFFERED BY THIS FACILITY.

   b) THAT ONE FACILITY OFFERING RESOURCES AT THIS POINT ON THE CONTINUUM IS ADEQUATE TO MEET THE NEEDS OF THE ADULT DISABLED POPULATION IN MANITOBA.

7. THAT THE CONCEPT OF "TRANSITIONAL LIVING", WHERE DISABLED RESIDENTS ARE OFFERED OPPORTUNITIES TO DEVELOP SELF MANAGEMENT SKILLS IN PREPARATION FOR MORE INDEPENDENT COMMUNITY LIVING, BE SUPPORTED AND ENCOURAGED IN ANY TYPE OF SETTING.

8. a) THAT SPECIAL LIVING ARRANGEMENTS FOR DISABLED ADULTS BE ESTABLISHED IN THE CITY OF BRANDON.

   b) THAT SUPPORT FOR THE SPECIAL PROJECT IN THE PAS BE CONTINUED.

   c) THAT OTHER REGIONAL LOCATIONS BE ASSESSED AS TO THE NEED FOR AND THE VIABILITY OF DEVELOPING SUCH RESOURCES.

   d) THAT THE TYPE AND SIZES OF LIVING ARRANGEMENTS BE ESTABLISHED IN CONSULTATION WITH THE ADVISORY COUNCIL RECOMMENDED IN SECTION IV, RECOMMENDATION 3, PAGE 10.

DISCUSSION:

Co-op living/housing may be another vehicle for the expansion of living options for the disabled.

It should be noted that:

a) Co-op housing is a non-profit housing development vehicle eligible for federal or provincial financing and assistance. The goals of this housing approach are both social and economic. Development and management are seen as a collaborative effort of all members (residents) of the cooperative. Appendix D, Part E identifies co-op developments which have welcomed disabled persons as fully integrated members of the project environment.

b) Co-op living provides a unique opportunity for members to build a community and to share and assist each other in ways beyond simply meeting a shelter need. The community is seen foremost as "people" with a conscious value base of mutual effort and support.

Appendix D, Part E, also provides examples of co-op living which centers around the support needs of disabled residents.

RECOMMENDATION:

9. THAT THE GOVERNMENT OF MANITOBA SHOULD INITIATE POLICIES AND PROCEDURES WHICH:

   a. ENCOURAGE CO-OP HOUSING SOCIETIES TO INCLUDE DISABLED PERSONS AS ACTIVE MEMBERS OF CO-OPS INTENDED FOR ALL SEGMENTS OF SOCIETY.

   b. ALLOW AND SUPPORT GROUP LIVING ARRANGEMENTS TO BE INTEGRATED INTO LARGER CO-OP ENVIRONMENTS/ PROJECTS.

   c. ENCOURAGE DISABLED GROUPS/ORGANIZATIONS TO SERVE AS THE IMPETUS OR SPONSORS OF CO-OP HOUSING DEVELOPMENTS INTENDED FOR A CROSS-SECTION OF THE LARGER COMMUNITY.

   d. RECOGNIZE THAT THE SELF HELP MODEL OF CO-OP LIVING IS AN OPTION WHICH MERITS FURTHER ANALYSIS AND WHICH MAY BE A VALID METHOD FOR PERSONS TO LIVE IN CO-OP SETTINGS WHERE SUPPORT TO THE DISABLED MEMBERS IS PROVIDED TO A LARGE DEGREE BY NON-DISABLED CO-OP RESIDENTS.

DISCUSSION:

To date, special attention to the varied needs of the disabled population have not been adequately addressed by planners and designers. Wheelchair accessible accommodation does not meet the needs of many client groups; for example, those who are auditorily or visually impaired. For many of these individuals, wheelchair suites are inappropriate and other forms of environmental adaptations are required.

RECOMMENDATION:

10. THAT THE GOVERNMENT OF MANITOBA DEVELOP A POLICY REQUIRING THAT GOVERNMENT ASSISTED HOUSING, WHETHER GOVERNMENTALLY OR PRIVATELY SPONSORED, SHOULD INCLUDE UNITS DESIGNED TO MEET THE SPECIAL NEEDS OF ALL THE DISABLED.

DISCUSSION:

For disabled adults who do not require more specialized living arrangements, it is recognized that there is a need to provide more affordable housing and more housing options in the marketplace.

RECOMMENDATIONS:

11. THAT THE CRITERIA FOR ELIGIBILITY FOR SHELTER ALLOWANCES BE AMENDED TO INCLUDE NON-ELDERLY, DISABLED INDIVIDUALS NOT CURRENTLY ELIGIBLE FOR THIS BENEFIT.

12. THAT THE FEDERAL-PROVINCIAL RENT SUPPLEMENT PROGRAM BE UTILIZED AS AN INCENTIVE FOR PROVIDING ALTERNATIVE HOUSING OPTIONS FOR DISABLED PERSONS.

DISCUSSION:

The need for adequate and reliable respite care facilities for disabled adults has been identified by a number of the individuals and groups responding to the task force. The stresses placed on primary care givers have been clearly identified.

It is important that staffing patterns for group living arrangements provide for adequate staffing relief to ensure continuity of care.

RECOMMENDATIONS:

13. a) THAT WHENEVER FEASIBLE, PROVISION BE MADE FOR RESPITE CAPACITY WITHIN SPECIAL GROUP LIVING FACILITIES.

    b) THAT ADDITIONAL RESPITE PROGRAMS BE SUPPORTED TO PROVIDE ADEQUATE RESPITE RESOURCES THROUGHOUT THE PROVINCE.

14. THAT THE SPONSORING AGENCIES FOR GROUP LIVING OR SPECIAL FACILITIES PROVIDE, WITHIN THEIR STAFFING COMPLEMENT, ADEQUATE ARRANGEMENTS FOR STAFF RELIEF.

DISCUSSION:

Members of the disabled community have identified a number of issues relating to living arrangements which must be addressed during the planning and implementation of alternative housing facilities. These include: maintenance of personal privacy; accessibility in terms of location to shopping, banking and other services; access to reliable transportation; inclusion of safety factors, but wherever possible these should not compromise opportunities for personal independence; and the opportunity for residents to direct their own resources where appropriate.

RECOMMENDATION:

15. THAT DEVELOPMENT OF SPECIAL HOUSING OR RESIDENTIAL FACILITIES FOR DISABLED ADULTS SHOULD BE UNDERTAKEN IN CONSULTATION WITH THE DISABLED COMMUNITY.

VI. DISABLED IN THE WORKPLACE

DISCUSSION:

The Task Force, in the course of its work, identified that vocational, educational and employment concerns which were raised by disabled adults in personal care homes and in the community, had to be examined within the context of this report. In examining the issue of the disabled in the workplace, the committee recognizes that a number of programs are involved in this area. These include Rehabilitation Services, Home Care, Manpower, Education and Training programs in both Federal and Provincial jurisdictions. The issues that must be addressed are far broader than any one program and must be dealt with as a whole. Review and coordination of this area should be vested in the coordinating body as previously recommended and identified in Policy Development, Section IV, Recommendation #4, Page 10.

RECOMMENDATIONS:

1. THAT FOR DISABLED INDIVIDUALS FOR WHOM TRAINING AND EMPLOYMENT OPTIONS ARE REALISTIC, A PROGRAM OF GOVERNMENT SHOULD RESPOND TO THEIR PERSONAL CARE NEEDS IN THE WORK PLACE. THIS ISSUE WILL REQUIRE FURTHER STUDY, IN CONSULTATION WITH DISABLED PERSONS.

2. THAT IN INSTANCES WHERE ALLOWANCES ARE AVAILABLE TO EMPLOYERS SO THAT THEY MAY PROVIDE THE PERSONAL ASSISTANCE REQUIRED BY DISABLED EMPLOYEES, SUCH FUNDED PROGRAMS SHOULD BE USED RATHER THAN THE DEPARTMENT OF HEALTH CONTINUING CARE PROGRAM.

3. THAT THE GOVERNMENT OF MANITOBA HAS A RESPONSIBILITY TO PROMOTE, THROUGH AFFIRMATIVE ACTION, AN ATMOSPHERE WHERE EMPLOYMENT OF THE DISABLED WILL BECOME AN INTEGRAL PART OF THE WORKPLACE. SPECIAL SERVICES FOR THE DISABLED WILL BECOME A PART OF GENERAL EMPLOYMENT PRACTICE AND WILL NO LONGER HAVE TO BE PROVIDED BY GOVERNMENTAL AGENCIES.

4. THAT PENDING THE REVIEW IDENTIFIED IN RECOMMENDATION #1 OF THIS SECTION, THOSE SERVICES RELATED TO BASIC CARE AND SAFETY OF THE INDIVIDUAL IN THE WORKPLACE SHOULD BE PROVIDED THROUGH THE CONTINUING CARE PROGRAM WHEREVER ASSISTANCE REQUIRED IN THE WORKPLACE CANNOT REALISTICALLY BE PROVIDED BY THE INDIVIDUAL, THE EMPLOYER, FELLOW EMPLOYEES OR VOLUNTEERS.

VII. HOME CARE

With the introduction of the province-wide Home Care program in 1974, Manitoba took the lead among provinces in Canada in support of independent community living. A broad range of services have been provided on the basis of individual need to prevent risk of institutionalization. With its integration with assessment for placement into care facilities, its centralized program direction and decentralized regional delivery, its single entry system and accessibility to all Manitobans, this program has been recognized for its comprehensiveness.

Through the first decade, which included The Year of the Disabled, many disabled persons have been able to achieve or maintain a level of independent community living. This has been accomplished with the support and participation of individual disabled persons, and organizations of disabled persons. Programs and services complementary to home care have been introduced, including medical/social rehabilitation, equipment and supplies, handi-transit, and vocation/employment/recreational opportunities. Not only have most adult disabled persons been able to remain in the community; many have been able to become active within their community.

However, the experience of this decade has also revealed gaps not previously recognized. New understandings of those program provisions, program delivery features and governmental structures, which promote or impede maximum independent community living for some disabled persons have emerged.

The Task Force considers that the basic tenets of the Home Care Program should be maintained as essential to community living for the disabled. As the recommendations which follow indicate, some modifications and expansions of program components, in combination with other recommendations made in this report can provide opportunity for new community living options.

Concerns have been raised regarding the delivery of service to the disabled by a private company. In consideration of the fact that a review of this situation is currently underway within government, the Task Force has chosen not to address this issue in this report.

DISCUSSION:

Some disabled persons have expressed the view that the Continuing Care Program should not take into account the services provided by families and community resources when assessing the need for required services.

Consistent with the philosophy of the Government of Manitoba to encourage self and community responsibility for health and social services, the Task Force supports the continuation of departmental policy to involve families and community resources in the provision of care to the disabled in the community.

Provision of services at present is based on assessed need. Some disabled persons have asked that service be based on categories such as diseases and degree of disability. This would lack both the flexibility to address individual variations in need and to provide for efficiency and fiscal responsibility. To some degree lack of flexibility within the present delivery system is often associated with insufficient resources.

RECOMMENDATION:

1. THAT TO THE GREATEST DEGREE POSSIBLE, FAMILY MEMBERS AND OTHER NEIGHBOURHOOD RESOURCES SHOULD CONTINUE TO PROVIDE SUPPORT SERVICES TO CLIENTS IN THE HOME CARE PROGRAM.

2. THAT THE PROVISION OF HOME CARE SERVICES CONTINUE TO BE BASED ON ASSESSMENT OF NEED AND THAT RESOURCES BE PROVIDED TO THE CONTINUING CARE PROGRAM TO ENSURE FLEXIBILITY OF THE DELIVERY SYSTEM.

DISCUSSION:

While some disabled persons have requested the removal of cost limits, the Task Force in considering this issue, recognizes that the removal of cost limits includes the risk that the needs of all disabled persons could be jeopardized as a result of government bearing high costs for a few individuals. This issue could be considered for further review when more options are in place.

RECOMMENDATION:

3. THAT THE COST OF HOME CARE SERVICES SHOULD NOT EXCEED THE COST TO GOVERNMENT OF CARE IN A HEALTH FACILITY EXCEPT IN VERY SPECIFIC INSTANCES, TO BE REVIEWED ON AN INDIVIDUAL BASIS.

DISCUSSION:

Some disabled persons have expressed the concern that focusing home care services on basic care and safety limits their scope for lifestyle choices. The Task Force acknowledges that this lack of provision for such needs as banking, recreation, shopping, etc. does inhibit lifestyle choices.

RECOMMENDATION:

4. a) THAT IT IS THE RESPONSIBILITY OF GOVERNMENT TO CONTINUE TO PROVIDE THOSE SERVICES WHICH ENSURE THE BASIC CARE AND SAFETY OF THE DISABLED INDIVIDUAL.

   b) THAT THE GOVERNMENT ALSO HAS A RESPONSIBILITY TO PROMOTE THE DEVELOPMENT AND UTILIZATION OF COMMUNITY RESOURCES TO PROVIDE SERVICES WHICH, ALTHOUGH NOT DIRECTLY RELATED TO BASIC CARE AND SAFETY, PROVIDE A QUALITY OF LIFE COMPARABLE TO THAT ENJOYED BY THE COMMUNITY AT LARGE.

DISCUSSION:

Some adult disabled persons in the community have requested that there be no limit to services provided; others have requested that there be a clear definition of the extent to which services will be provided. The Task Force takes the view that in total care or life risk situations, there are some inherent limits in the provision of basic care and safety through an itinerant service.

RECOMMENDATIONS:

5. THAT ARBITRARY SERVICE LIMITS NOT BE ESTABLISHED, THUS ENABLING THE HOME CARE PROGRAM TO TAKE ADVANTAGE OF NEW TECHNOLOGIES TO BROADEN THE SCOPE OF CARE IN THE HOME.

6. THAT THE PRESENT PROGRAM REQUIREMENT FOR FAMILY OR OTHER BACKUP IN TOTAL CARE OR LIFE RISK SITUATIONS BE CONTINUED.

DISCUSSION:

Several of the submissions to the Task Force called for a "guarantee" of service "on demand" as necessary to achieve independent lifestyle, while others requested "self-direction of care providers." It is our view that while these concepts could provide increased opportunity for normal living for some, they cannot be realistically introduced into the total Home Care program. More might be achieved through the Home Care program with more service delivery options. These could be demonstrated through the development of pilot projects.

For some disabled persons who live in their own homes, and whose handicaps are extensive or whose conditions are unstable, a delivery mode which incorporates the advantages of the "Fokus" model, including developmental participation by the disabled consumer, may provide improved service. This would require a specially organized group of care providers for a specific group of disabled persons living within an identified geographic area. This type of service delivery would require more intensive staffing, coordination and monitoring than is presently available.

For still other disabled persons, a one-to-one, twenty-four hour accessible attendant care service similar to that developed to some degree in other jurisdictions may provide the desired opportunity for more autonomous independent living.

RECOMMENDATIONS:

7. THAT THE OFFICE OF CONTINUING CARE AND WINNIPEG REGION BE ALLOCATED THE NECESSARY RESOURCES TO INITIATE A PILOT PROJECT FOR DELIVERY OF SERVICES COORDINATED ON A GEOGRAPHICAL "GROUP BASIS" WHICH WOULD BE DESIGNED TO PROVIDE CLIENTS WITH THE MAXIMUM POTENTIAL FOR FLEXIBILITY AND SELF-DIRECTION.

8. THAT DISCUSSION TAKE PLACE BETWEEN GOVERNMENT AND APPROPRIATE AGENCIES WITH A VIEW TO ESTABLISHING A COMMUNITY BASED, NON-PROFIT ORGANIZATION TO BE RESPONSIBLE FOR THE DEVELOPMENT OF A PILOT PROJECT TO TEST THE POTENTIAL FOR A SELF DIRECTED ATTENDANT CARE PROGRAM.

DISCUSSION:

The need for provision of no cost incontinent supplies for self-care persons with chronic incontinence has been identified as a priority. This will achieve service economy and maximum client independence. The availability of these supplies is a prerequisite to extending services to the workplace (See Section VI, Page 19).

RECOMMENDATION:

9. THAT SUPPLIES FOR THE MANAGEMENT OF CHRONIC INCONTINENCE BE MADE AVAILABLE AT NO COST TO CONSUMER THROUGH THE HOME CARE EQUIPMENT AND SUPPLIES PROGRAM OF THE DEPARTMENT OF HEALTH. THAT ASSESSMENT FOR AND INSTRUCTION IN THE USE OF THESE SUPPLIES BE PROVIDED BY THE CONTINUING CARE PROGRAM.

DISCUSSION:

Some family members have requested that they be reimbursed to provide services for disabled relatives rather than the program employing others. Other consumers have requested an allowance to enable them to purchase service directly. There has been limited experience with the payment of relatives or clients in other jurisdictions with mixed results.

RECOMMENDATION:

10. a) THAT THE GOVERNMENT CONTINUE TO CONSIDER THE ISSUE OF REIMBURSING RELATIVES FOR ATTENDANT SERVICES.

    b) THAT THE OPTION OF PROVIDING FUNDING DIRECTLY TO DISABLED PERSONS SO THAT THEY BECOME THEIR OWN HIRING AUTHORITY BE ADDRESSED BY THE COORDINATING BODY IDENTIFIED IN SECTION IV, RECOMMENDATION #1, PAGE 10.

DISCUSSION:

Various submissions have indicated problems related to lack of adequate staff training. In addition, the differences in the provision of service for adult disabled persons as opposed to other clients have been identified as a problem.

Special recognition must be made of the fact that disabled clients require a significant amount of staff time. Adequate training and preparation for workers in this field is essential. In recognition of the importance of training, a special training program has been developed by the Continuing Care program, in conjunction with Red River Community College.

RECOMMENDATION:

11. a) THAT THE TRAINING OF STAFF CONTINUE TO BE IDENTIFIED AS AN ESSENTIAL COMPONENT OF THE HOME CARE SERVICE FOR DISABLED ADULTS.

    b) THAT RESOURCES SHOULD CONTINUE TO BE ALLOCATED FOR THE TRAINING OF HOME CARE STAFF.

APPENDICES

APPENDIX A

MEMBERS OF THE TASK FORCE

CHAIRMAN:	K. THOMSON DIRECTOR, PERSONAL CARE HOMES DIVISION MANITOBA HEALTH SERVICES COMMISSION
VICE-CHAIRMAN/SECRETARY:	C. J. SARCHUK STANDARDS OFFICER PERSONAL CARE HOMES DIVISION MANITOBA HEALTH SERVICES COMMISSION
MEMBERS:	R. ASSELIN PROGRAM ANALYST, RESEARCH & PLANNING DEPT. OF COMMUNITY SERVICES AND CORRECTIONS
	T. BAINS REGIONAL COORDINATOR COMMUNITY MENTAL HEALTH PROGRAMS DEPARTMENT OF HEALTH
	B. HAVENS PROVINCIAL GERONTOLOGIST DEPARTMENT OF HEALTH
	E. THOMPSON DIRECTOR, CONTINUING CARE DEPARTMENT OF HEALTH
	M. WATTS PROGRAM COORDINATOR MENTAL RETARDATION PROGRAMS DEPT. OF COMMUNITY SERVICES AND CORRECTIONS
	J. ZAMPRELLI MANAGER, POLICY RESEARCH & ANALYSIS BRANCH DEPARTMENT OF HOUSING

APPENDIX B

FACILITIES VISITED BY TASK FORCE MEMBERS

1. BEACON HILL LODGE - WINNIPEG
2. EAST VIEW LODGE - NEEPAWA
3. FAIRVIEW HOME - BRANDON
4. HILLCREST PLACE - BRANDON
5. HOLY FAMILY NURSING HOME - WINNIPEG
6. LUTHER HOME - WINNIPEG
7. MAPLES PERSONAL CARE HOME - WINNIPEG
8. MUNICIPAL HOSPITAL - WINNIPEG
9. REHABILITATION CENTRE - WINNIPEG
10. SWAN RIVER VALLEY PERSONAL CARE HOME - SWAN RIVER
11. TACHE NURSING CENTRE - WINNIPEG
12. TEN TEN SINCLAIR HOUSING INC. - WINNIPEG

APPENDIX C

GROUPS AND INDIVIDUALS RESPONDING TO CALL FOR SUBMISSIONS

1. ALTERNATE HOUSING COMMITTEE - CEREBRAL PALSY ASSOCIATION OF MANITOBA
2. CANADIAN PARAPLEGIC ASSOCIATION (MANITOBA DIVISION)
3. MANITOBA ASSOCIATION ON GERONTOLOGY
4. THE MANITOBA LEAGUE OF THE PHYSICALLY HANDICAPPED INC.
5. MANITOBA ASSOCIATION OF LONG TERM CARE
6. INDEPENDENT LIVING COMMITTEE OF THE MENNONITE CENTRAL COMMITTEE (MANITOBA)
7. MRS. E. KRAHN - BRANDON
8. MULTIPLE SCLEROSIS SOCIETY OF CANADA (MANITOBA DIVISION)
9. PHYSICALLY HANDICAPPED CONCERNS ON CAMPUS
10. RESOURCE CENTRE ON DISABILITIES
11. THE SOCIETY FOR CRIPPLED CHILDREN AND ADULTS OF MANITOBA
12. SPINA BIFIDA ASSOCIATION OF MANITOBA
13. TEN TEN SINCLAIR HOUSING INC.
14. WINNIPEG LEAGUE FOR THE HARD OF HEARING

APPENDIX D

ALTERNATE HOUSING MODELS

A CROSS CANADA PERSPECTIVE

A. QUASI-INSTITUTIONAL CARE FACILITIES

Nigel House - Victoria, British Columbia

Operated by the Vancouver Island Housing Association of the Physically Disabled; provides 41 residents, aged 19 to 65, with 4 hours a day nursing care, 24 hour attendant care, housekeeping and meals.

Residents have a variety of disabilities (e.g., paraplegia, multiple sclerosis (MS), cerebral palsy (CP), brain injury) and are offered a "protective atmosphere" in which they are expected to maximize self-direction.

False Creek Residence - Vancouver, British Columbia

A 23 bed facility funded through the Long Term Care Program of British Columbia.

It has been in operation for six years and was initiated by parents who were advocating for a viable alternative to placing their children in extended care units with the elderly.

Residents, with a variety of disabilities (traumatic injury, MS, CP, Spina Bifida) come from traditional care institutions or family homes.

The community based board is composed of parents, consumers and interested community persons. The goal is to get residents involved in activities or services (recreational, work, physiotherapy) outside of the facility.

Staff provides attendant care.

There are two categories of residents:

1) Those who can use the residence as a "pass through" to more integrated options (apartment living, group homes).

2) Those who will remain because the residence offers them maximum opportunity for independent living.

Participation House - Binbrook, Ontario

A residential complex for both physically handicapped and developmentally delayed adults, aged 18 to 50. The objective is to provide medical care and help create an environment in which the individual can maximize potential for self-sufficiency.

There are three modules of twelve units each with shared bath, communal spaces, dining, etc. The major operational departments of the facility are residential care, developmental programming, occupational therapy and recreation.

B. TRANSITIONAL HOUSING

Ten Ten Sinclair - Winnipeg, Manitoba

Ten Ten Sinclair is an apartment complex with 75 fully self-contained suites, architecturally designed to facilitate practical experience in independent wheelchair living. It provides an integrated residential setting for 25 severely handicapped, 25 moderately handicapped and 25 non-handicapped tenants and contains common space such as lounge, library, dining and recreation areas.

The primary function of Ten Ten Sinclair is to serve as an interim residence where persons with a variety of disabilities can gain practical experience in all areas of residential living. The goal is to develop the skills and the resources needed to function independently in the community. Staff and tenants work together in planning new and improved forms of community living opportunities. Tenants are assisted in making the transition into the community when the "Ten Ten" experience is complete.

Attendant care staff are available to meet individual requirements on a shared service basis. Tenants are encouraged to make their own arrangements as to schedules and other help required. In addition to providing for personal care needs, assistance is available for housekeeping services, laundry and meal preparation on an individual basis. Where there are specific medical needs tenants are required to make their own arrangements. Information is available with respect to the provision and use of special aids and appliances and tenants are encouraged to "experiment" with devices supplied on loan. A library service is being developed to offer "new ideas" with respect to self-help and independent functioning.

Villa de Repos - Moncton, New Brunswick

The Villa was modeled quite extensively on "Ten Ten Sinclair".

The program in terms of goals, transitional housing experience is almost a replica of Ten Ten, whose administration provided the Villa with frequent consultation and advice.

The complex was developed in co-operation with the New Brunswick Department of Health. The target age group is 18-40, although applications from older adults are considered. The complex incorporates 34 single apartments and 18 hostel units located around a common dining room and kitchen area. The hostel component will provide a group living situation for residents who are unable to live independently in their own apartment. Personal care and support services are available. Rents are geared-to-income, with provincial government subsidies.

150 Castlegreen Drive - Thunder Bay, Ontario

A complex of 20 bachelor and four 2 bedroom units designed to provide housing for young disabled persons who "demonstrate the capacity, motivation and drive to upgrade and improve their standard of living" and will benefit from management's intent to assist each individual to "assume total responsibility for governing his/her life."

When residents of this transitional living centre achieve their optimum level of independence, they move on to one of the two "satellite projects" which like the centre are administered by the Handicapped Action Group, Inc.

C. GROUP LIVING (GROUP HOMES/COMMUNITY RESIDENCE)

Centres Offering Independent Lifestyles (COIL) - Saint John, New Brunswick

COIL is a recently initiated model which merits further exploration. This is a newly constructed (Sec. 56.1 non-profit) group home serving six physically disabled residents, aged 18-40. It is seen as an alternative to institutional care. It is a single level building designed with two 3 bedroom modules, common baths, dining, etc.

Residents are encouraged to reach their maximum level of independence, and they are involved in decision making regarding the functioning of the house; e.g., they handle the food budgeting and purchasing, and do 75% of meal preparation. The staff of 6 are present in shifts, but do not live in; 2 at peak periods, 1 otherwise, day and night.

Cheshire Homes, Inc.

Canada's Cheshire Homes take one of two forms. The most popular is the shared facility, or group home, most of which are renovated single-family dwellings in residential neighbourhoods, close to shopping and transportation. The second is the apartment or "independent living model".

These homes, located primarily in Ontario and Saskatchewan, have a common goal to create a "permanent place of shelter for physically disabled individuals; a home where people can feel they belong and have a permanent stake."

The Cheshire Foundation provides continuing support to member homes, residents/tenants through the promotion and development of standards of service, exchange of information, liaison with government authorities, on-site training, etc.

Examples of this model are:

a) Quinte Cheshire Home - Belleville, Ontario

A 10 person group home providing 24 hour attendant care/supervision as well as assistance in the development of life skills. Residents are expected to be involved outside of the home in terms of education, employment, sheltered workshop, volunteer activities. As well, the group is expected to contribute to doing housework, cooking, etc. For a small number of persons, the home has served as a transitional setting leading to independent living.

b) Cheshire Homes of Regina - Regina, Saskatchewan

The home is a newly constructed group setting for 10 residents, most of whom have CP. There are 1 to 2 staff persons available on-site for most of the 24 hour period. During its two years of existence, the home has helped residents work towards greater independence.

c) Ashby House Group - Toronto, Ontario

Ashby House was established in 1974 as a group home for young adults with head injuries. The rehabilitation programs are directed toward developing cognitive and social skills. After the initial stage of rehabilitation at Ashby House, residents move into apartments where the concentration is on learning independence, fostering a sense of responsibility, and developing psycho-social skills, with the objective of being integrated into the community. Ashby House can accommodate 5 residents between the ages of 17 and 35, who do not require ongoing medical or nursing care and who are not wheelchair users.

The above are only a few examples of the living arrangements sponsored by Cheshire Homes for the disabled in Canada. As stated, the organization offers a range of opportunities from fairly sheltered to community integrated.

D. INDEPENDENT LIVING WITH SUPPORT

Integrated apartment style living with support/attendant care to accommodate even the severly disabled is, as a contemporary option, gaining momentum in North America.

Manitoba, with its three Fokus Housing sites has been in the vanguard of this movement. There are a number of other examples which can be drawn upon to demonstrate the importance which this option holds for creating opportunities for independent living.

Fokus Manitoba - Winnipeg, Manitoba

Fokus Manitoba provides modified apartments with attendant care and household supports to facilitate independent, integrated living for capable, severely disabled adults. Currently there are three Fokus sites, the first established in 1978 at a family public housing project (8 tenants), the second (15 tenants) and third (12 tenants) beginning in 1980 and 1982 respectively, both housed in commercial apartment buildings. Fokus is predicated on a philosophy of independent, integrated community living.

There are several organizations which have cooperated in the planning and delivery of the Fokus program.

a) The Provincial Home Care Program - provides assessment to determine the nature and extent of services required in accordance with program guidelines; purchases attendant care staff time from Ten Ten Sinclair (page 30); provides household services directly and is responsible for overall program supervision. Staff are available 24 hours a day but do not live in.

b) The Provincial Department of Housing - has funded building and unit modifications and provided ongoing rental supplements to qualifying tenants through the Winnipeg Regional Housing Authority.

c) Ten Ten Sinclair - coordinates the efficient functioning of the Fokus units, provides supervision of attendant staff and coordinates tenant selection and placement.

d) Tenants - have been actively involved as a group with each project in the development of the unit, in the selection of participants and in the planning of the service component.

Rehabilitation Institute of Ottawa (RIO)
Integrated Housing Project - Ottawa, Ontario

Two RIO housing projects provide accessible housing and attendant care available 24 hours a day to physically disabled adults in an integrated setting. Fifteen units are dispersed throughout one high-rise apartment building and an additional twelve units are located in another building. The units have been minimally renovated for accessibility. Rent is based on income according to the Ontario Housing Corporation's Rent Supplement Program. Attendant care is funded by the Ministry of Community and Social Services, and is provided with a view to maximizing independence.

Twenty Emerald North - Hamilton, Ontario

Sixteen modified units in a larger apartment block (217 units) with attendant care available on-site on a 24-hour, as required, basis. Assistance is provided for personal care, meal preparation, housekeeping, laundry and shopping. Applicants aged 18-40 years are given a high priority for admission.

Tenants must be prepared to direct their own attendant care program, make decisions with regard to support required for activities of daily living, and establish their needs with the staff (10 full/part-time).

Guelph Independent Living Project - Guelph, Ontario

This project, which opened in 1983, offers 10 apartment units in a 15 storey high-rise building to disabled persons. The tenant must be capable of benefiting from an independent housing alternative and have a desire to become more fully integrated into the community. Tenants range from age 18 to 57 and have a range of care needs. Rents are subsidized by the Ontario Housing Corporation and the support services are funded by the Ministry of Community and Social Services.

E. COOPERATIVE HOUSING FOR PEOPLE WITH SPECIALIZED NEEDS

Superior View Housing Co-op - Thunder Bay, Ontario

Superior View Housing Co-op with a total of 80 units is a component of a larger Co-op Housing Development which includes Castlegreen Co-op Housing (See Section B, page 31). The co-op was developed with the objective of providing housing for both the non-disabled and persons with special needs.

33 of the Superior View Housing Co-op units are designated for persons with special needs. Among this group there are persons with developmental disabilities; those who are graduates from the Castlegreen Co-op Transitional Housing Facility (similar to Fokus Manitoba) and those who are disabled but require only intermittent support/care.

Ceci Homes - Toronto, Ontario

Ceci Homes, which are group residences for children with multiple handicaps (21 full-time, 7 respite), is an integrated part of the Cathedral Court Cooperative which is one of the many housing components of the St. Lawrence Neighbourhood Development Project.

A distinguishing aspect of this co-op is the role that the Ceci Foundation played in forming and developing the larger project. The Foundation was the sponsor of the co-op and instrumental in obtaining Federal/Provincial financing.

Ceci is an example of the special need group serving as the impetus to developing co-op housing which meets both the needs of its own constituents as well as housing needs of the larger community.

Prairie Housing Co-op - Winnipeg

This is an example of cooperative living based on a mutual support system where both disabled and non-disabled members live in the same unit or in close proximity.

The goal is to create "natural" opportunities for interaction between the two who work together to arrange additional personal supports which some members require and which may be provided on a voluntary basis by one's "neighbour" or co-habitant.

F. TECHNICAL RESOURCE SUPPORT GROUPS.

Particularly in the area of co-op and non-profit housing a number of technical resource support groups are developing throughout the country. Some of these groups have as a specific objective the development of housing alternatives for the disabled.

One example of such a group is Building Independent Living with the Disabled (BILD) in Vancouver, B.C.

APPENDIX E

DEMOGRAPHIC DATA AND PROFILE

1. SUMMARY OF DEMOGRAPHIC OBSERVATIONS

a) There were 249 individuals under the age of sixty in personal care homes at the time diagnostic data was compiled in March 1983.

b) There were equal numbers of men and women.

c) These individuals were, on average, much younger than the overall average age of personal care home residents; about 50 years compared to over 80 years of age.

d) The most frequent categories of diagnosis for men were:

1) central nervous system dysfunction with physically disabling effects (for example, multiple sclerosis);

2) systemic disease (for example, diabetes); and

3) mental retardation.

The three categories accounted for 20.2% of men under 60 years of age.

e) The most frequent category of diagnosis for women was the specific diagnosis of multiple sclerosis. Nearly one-quarter of women under the age of sixty in personal care homes had this diagnostic information.

f) Individuals under the age of sixty waiting for placement into personal care homes were, on average, even younger than the similar group already residing in personal care homes; 47 years compared to 50 years.

g) The most frequent categories of diagnosis for those waiting for placement were mental retardation, congenital disabilities and central nervous system dysfunction.

h) There were more women (64.5%) among those waiting for placement than men (33.5%).

i) Two personal care homes in Winnipeg account for 48% of all those waiting for placement.

2. DIAGNOSTIC INFORMATION

Disabled adults residing in Manitoba's personal care homes have a variety of diagnoses. This diagnostic information is recorded at the Manitoba Health Services Commission, and corresponds to morbidity codes in the "International Classification of Diseases" (Revision 8 and 9). Since there are literally hundreds of such codes it was necessary to develop aggregate or summary categories that would group together similar diagnoses permitting an overall view, in medical terms, of why these individuals are residing in personal care homes. Twelve categories were defined that grouped diagnostic information on the basis of the general functional effect of a diagnosis.

3. CATEGORY DEFINITIONS

CATEGORY	DEFINITION	EXAMPLES
1	Central nervous system (CNS) dysfunction, disease, damage or degeneration from organic causes with specific mention of physically disabling effect.	- multiple sclerosis - Huntington's chorea - cerebral palsy - late effects of Cerebro-vascular Disease (CVD) - intra cerebral hemorrhage - parkinsonism - other cerebral degeneration and brain conditions May include epilepsy and other convulsive disorders if physically disabling effects are noted. Effects include paraplegia, hemi-plegia, quadriplegia and spastic paralysis.
2	CNS dysfunction, disease damage or degeneration from organic causes without specific mention of physically disabling effects or with low likelihood of physically disabling effects.	- Alzheimers disease - epilepsy - aphasia - other convulsive disorders - other cerebral degeneration
3	Sensory impairment	- speech impairment - hearing loss - sight loss

CATEGORY	DEFINITION	EXAMPLES
4	Systemic organic disease, organic trauma and infectious agents with no specific mention of disabling effects.	- diabetes with and without complications - rheumatoid arthritis - metabolic and hemoglobin disorders - arteriosclerosis - heart failure
5	Mental illness and personality disorders resulting apparently from CVD with specific mention of accident, disease or degeneration.	- psychoses - depression - paranoia - schizophrenia
6	Mental illness and personality disorders resulting apparently from organic insult or sudden organic injury.	Etiology includes accident trauma, postconcussion syndrome and alcoholic and nonalcoholic amnestic syndromes. See category 5 for examples.
7	Mental illness and personality disorders without mention of apparent etiology.	See category 5 for examples
8	Acquired physical disabilities and musculoskeletal deformities resulting in physical disabilities.	Etiology includes accident trauma. - paraplegia - hemiplegia - quadriplegia - scoliosis - deformity of limb
9	Congenital anomalies with debilitating physical and intellectual effects.	- spina bifida - hydrocephalus
10	Neoplasms. Malignant, benign and uncertain behaviour, all sites, primary and secondary oncogenesis.	- bladder cancer - brain cancer - prostate cancer - leukemia
11	Mental retardation without mention of other conditions.	- Down's syndrome - mild, moderate or unspecified mental retardation.
12	Miscellaneous conditions and conditions otherwise unclassifiable due to scant diagnostic messages.	- unspecified birth damage or trauma - unspecified effect of injury, concussion, etc. - surgical aftercare - dental caries - alcohol dependence

4. SIMPLIFYING MULTIPLE DIAGNOSES

The majority of individuals had more than one, and as many as three diagnoses. These were called the primary, secondary and tertiary diagnostic messages. Cases with tertiary messages could not be plotted or placed on a standard two-dimensional graph and so had to be "reduced" to a message with just primary and secondary diagnostic information. This then allowed these more complex diagnoses to be graphed.

To ensure consistency in the way triplet messages were reduced, a total of six data reduction rules were defined. The technical rules are available from the Task Force on request.

5. AGE AND SEX

In total, there were 254 individuals under the age of sixty in personal care homes at the time the diagnostic data was compiled (March 1983). However, one was younger than eighteen, and four others were missing diagnostic information, bringing the total to 249. Most were at the upper end of the age range; when divided in three age groups, the young (24-35 years), the middle (36-47 years), and the eldest (48-59 years), nearly three-quarters (71.4%) were in the eldest category. Only six percent were in the youngest grouping, with the remaining 23% in the middle group (See Table 1, Page 44).

There was nearly the same number of men as women; respectively 125 and 124. They followed a similar pattern when broken into the age categories noted above: 4.8% of women and 7.2% of men were in the youngest group; 24.2% of women and 20.8% of men were in the middle group and 70.9% of women and 72.0% of men were in the oldest group.

In the general population the number of men and women in these age categories are also very close, never being more than one-half of one percent different. Unlike the population at large, there is a much greater proportion of individuals in the eldest group among these disabled individuals. While only about 10% of the general population is between 48 and 59 years of age, nearly three-quarters of this group of disabled persons are that age.

There does not seem to be a single clear profile of disabled adults in personal care homes outside of a tendency for their ages to cluster in the 48 to 59 age group. Even so, they are distinct as a group from other personal care home residents, whose average age is 83 years.

6. DIAGNOSTIC INFORMATION

Of all the groups of disabled persons in personal care homes, the most frequent (43.3%) primary diagnosis was central nervous system damage or degeneration, including both progressive diseases and the late effects of a cerebrovascular accident as causes. Those with CNS dysfunction diagnoses generally have a second diagnosis. While these other diagnoses vary, there is a clustering of organic and systemic diseases, and acquired physical disabilities.

Individuals with more than one diagnosis are examples of, "diagnostic interactions." The most prevalent diagnostic interactions are:

a) central nervous system dysfunction plus systemic organic disease; e.g., the late effects of a cerebrovascular accident with diabetes (categories 1 and 4 in the category definitions);

b) central nervous system dysfunction plus acquired physical disability; e.g., multiple sclerosis and hemiplegia (categories 1 and 8 in the category definitions); and

c) systemic organic disease plus personality disorders; e.g., rheumatoid arthritis and schizophrenia (categories 4 and 5 in the category definitions).

These three pairs or classes of diagnostic information account for 24.5% of all cases with more than one diagnosis.

Though men and women are equally represented in this group of disabled individuals, they appear to be personal care home residents for quite different reasons. Among women, the single most prevalent diagnosis, whether alone as a single diagnostic message or as the primary diagnosis in a group of diagnostic messages, was multiple sclerosis (classified into category 1, that is CNS damage with physically disabling effects). Virtually a quarter (24.2%) of all women had a primary diagnosis of multiple sclerosis.

For men, the diagnostic reasons associated with personal care home residency were, in order of decreasing importance, CNS dysfunction with physically disabling effects with systemic disease, acquired physical disabilities with systemic disease and mental retardation.

In summary, while this group of disabled individuals is older than the population at large, they are much younger than most other personal care home residents whose averge age is 83 (the average age of these disabled persons is about 50 years). Though they are almost equally likely to be men as women, men are more likely to have a diagnosis of a central nervous system dysfunction plus a systemic disease while women are more likely to have the diagnosis of multiple sclerosis.

7. PERSONAL CARE HOMES

Within some personal care homes there is an apparent tendency to specialize in the care of residents with certain types of diagnoses. Whatever the reason, there were eight homes that had many more residents with certain diagnoses than could be expected purely on the basis of chance. These findings are logical rather than statistical, and should be considered as an indicator rather than direct evidence. Details are available from the Task Force on request.

8. DIAGNOSIS AND REGION

In percentage terms almost two thirds (63.7%) of this group of disabled persons in personal care homes are in the Winnipeg region. Since only 55% of Manitoba's population aged 18 to 59 years lives in the region, Winnipeg is overrepresented in terms of this group. Based on population, Westman and Parklands region are also overrepresented. These three regions account for 85% of this group. The others are underrepresented, having less than their share based on population.

As noted above, 63.7% of the adult disabled residents in personal care homes are in the Winnipeg region. The distribution in the rest of the province follows: Westman - 13.5%, Parklands - 8.4%, Central - 5.9%, Eastman - 5.2%, Norman - 1.9%, Interlake - 0.8%, and Thompson - 0.4%.

There is also some specialization by diagnosis within regions just as there is in some personal care homes. Details are available from the Task Force on request.

9. DISABLED ADULTS AWAITING PLACEMENT IN PERSONAL CARE HOMES

There are, as noted earlier, 249 adults with disabilities between the ages of 18 and 59 years residing in personal care homes in Manitoba. There is a similar group of 31 adults that were, in March 1983, waiting for a place in a personal care home (See Table 2, Page 45).

On the whole, these individuals were younger than the same group already in personal care homes. Though few in absolute terms, 12.9% were in the youngest age group (24-35 years), compared to only six percent of those already living in personal care homes. Twenty-nine percent of those waiting were in the middle age category (36 - 47 years) while only 23% of disabled residents were this age. Lastly, somewhat more than half (58.1%) of those waiting were in the eldest age category (48-59 years), compared to nearly three quarters (71.4%) of the resident group. The average age of those awaiting placement was about 47 years as compared to 50 years for the resident group.

Unlike the resident group of younger disabled persons, in which men and women were very nearly equal in number, the group awaiting placement were more likely to be female (61.3%).

10. PERSONAL CARE HOMES AND DIAGNOSIS

Among those individuals waiting for placement in personal care homes, central nervous system dysfunction from either disease, damage or other degeneration with physically disabling effects was by far the most common diagnosis (38.7%). When combined with CNS dysfunction without or with no mention of physically disabling effects (category 1 plus category 2), the number with this diagnosis went to 55% of the total, exceeding the rate for residents (43%).

Acquired physical disabilities was the second most prevalent category of diagnosis (16%). Together, these two classes of dysfunction account for 70% of the waiting list.

Those awaiting placement are more likely to have mental retardation, congenital disability and CNS dysfunction disease or damage without specific mention of, or with a low expectation of physically disabling effects as a primary diagnosis (categories 11, 9 and 2). On the other hand, they are less likely to have as a recorded primary diagnosis systemic disease (category 4) or acquired personality disorders (category 6). Acquired physical disabilities and oncogenic diagnoses (categories 8 and 10) appear with approximately the same frequencies.

The 31 listed cases were waiting for placement into 16 different personal care homes. One home in Winnipeg accounts for virtually a third (32.3%) of the waiting list; with one additional home added in Winnipeg, these two account for nearly half (48.3%) of the list, and when a third personal care home is added in Westman, somewhat more than half the list is accounted for. Each of the 13 remaining identified personal care homes has one case listed for future placement.

This distribution among those awaiting placement suggests that because of experience or particular competence certain personal care homes exert a kind of "pull" on those needing service. However, when the diagnoses are examined, only two homes make up the bulk of the intended residence for the most prevelent diagnostic category. In other words, for the most frequent reason for placement (i.e., CNS dysfunction with physically disabling effects) 66% of the cases have been panelled for placement into either one or the other of the two Winnipeg personal care homes. These same two personal care homes in Winnipeg were found to specialize in this same diagnosis (CNS dysfunction with physically disabling effects) among their residents as well. The remaining third of the cases with this diagnosis (four cases) are split equally into four other homes. This clustering does not occur for any other diagnosis with the exception of a small grouping of persons with acquired physical disabilities (the number is very small for this latter diagnosis).

11. MENTAL RETARDATION AND MENTAL ILLNESS

Among both personal care home residents and those waiting for placement there are 60 individuals with the specific diagnosis of mental retardation or mental illness. These individuals are more likely to be male, unlike both the larger waiting list and the overall resident group (See Table 3, Page 46).

Overall, the age of those in this group tend to be about the same, on average, as those waiting for placement (about 46 years). This is not true, however, when men are separated from women; in this group, men are on average 46 years of age; women are on average 44 years of age.

As might be expected, mental illness and mental retardation appear much more often as a primary diagnostic reason for placement than any other: 54% of this group has one of these diagnoses as a primary diagnosis compared to only 10.5% of the entire group. The categories of congenital disabilities and central nervous system dysfunction without mention of physically disabling effects also appear slightly more often as a primary diagnostic reason for this sub-group. Mental illness as a primary diagnosis by itself appears less often in this group than in the overall resident group (less than 5% compared to 14%).

TABLE 1: AGE AND SEX OF PCH RESIDENTS UNDER 60 YEARS OF AGE IN %* (ACTUAL NUMBER)

SEX	AGE IN YEARS			
	24-35	36-47	48-59	TOTAL
MALE	7.2 (9)	20.8 (26)	72.0 (90)	50.2 (125)
FEMALE	4.8 (6)	24.2 (30)	70.9 (88)	49.8 (124)
TOTAL	6.0 (15)	22.5 (56)	71.4 (178)	100.0 (249)

* Percentages calculated horizontally except right hand totals.

TABLE 2: AGE AND SEX OF THOSE WAITING PCH PLACEMENT UNDER 60 YEARS OF AGE IN %* (ACTUAL NUMBER)

SEX	AGE IN YEARS			
	24-35	36-47	48-59	TOTAL
MALE	0.0 (0)	41.7 (5)	58.3 (7)	38.7 (12)
FEMALE	21.1 (4)	21.1 (4)	57.8 (11)	61.3 (19)
TOTAL	12.9 (4)	29.0 (9)	58.1 (18)	100.0 (31)

* Percentages calculated horizontally except right hand totals.

TABLE 3: AGE AND SEX OF P.C.H. RESIDENTS AND THOSE WAITING PLACEMENT WHO ARE ALSO ON MENTAL RETARDATION AND MENTAL HEALTH CASELOADS IN % (ACTUAL NUMBER)

SEX	AGE IN YEARS			
	24-35	36-47	48-59	TOTAL
MALE	15.8 (6)	21.0 (8)	63.2 (24)	63.3 (38)
FEMALE	27.3 (6)	27.3 (6)	45.4 (10)	36.7 (22)
TOTAL	20.0 (12)	23.3 (14)	56.7 (34)	100.0 (60)

* Percentages calculated horizontally except right hand totals.